

*Application of Information Technology* ■

# Overcoming Structural Constraints to Patient Utilization of Electronic Medical Records: A Critical Review and Proposal for an Evaluation Framework

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**Abstract** There are constraints embedded in medical record structure that limit use by patients in self-directed disease management. Through systematic review of the literature from a critical perspective, four characteristics that either enhance or mitigate the influence of medical record structure on patient utilization of an electronic patient record (EPR) system have been identified: environmental pressures, physician centeredness, collaborative organizational culture, and patient centeredness. An evaluation framework is proposed for use when considering adaptation of existing EPR systems for online patient access. Exemplars of patient-accessible EPR systems from the literature are evaluated utilizing the framework. From this study, it appears that traditional information system research and development methods may not wholly capture many pertinent social issues that arise when expanding access of EPR systems to patients. Critically rooted methods such as action research can directly inform development strategies so that these systems may positively influence health outcomes.

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Electronic patient record (EPR) systems fundamentally change the way health information is structured. An EPR is a dynamic entity, affording greater efficiency and quality control to the work processes of clinicians by providing data entry at the point of care, logical information access capabilities, efficient information retrieval, user friendliness, reliability, information security, and a capacity for expansion as needs arise.<sup>1,2</sup>

An EPR system promotes patient participation in care to a greater extent than paper records because of its capacity for interaction. Patients can transmit real-time vital signs and other forms of data from their bedside, home, or office and receive up-to-date supportive information customized and contextualized to their individual needs.<sup>3,4</sup>

In this journal, Ross and Lin recently presented a comprehensive review of the world literature on the effects of patient access to medical records, noting a potential for modest benefits and minimal risk, while also citing that the impact of access may vary depending on the patient population in question.<sup>5</sup> This is consistent with findings in the information system literature that systems fail when inadequate attention is paid to stakeholder needs and work processes during

design<sup>6</sup> or when assumptions are made about how well a system fits with the user's role within the organization during implementation.<sup>7</sup>

Medical records are structured primarily for the use of clinicians and administrators. Patients typically are not counted among the primary users of an EPR system. They tend to be given access sometime after the system is implemented in the organization. Structural concessions and decisions made when the system is first implemented, such as fragmented data entries and foreign lexicons, can make the information difficult for patients to follow and the records all but impossible for them to effectively use.<sup>8</sup>

## Background

Most limitations of paper medical records are structural in nature and include unavailability at the point-of-care (a single medical record cannot be in multiple places at once), inconsistent legibility (structure supports manual entries, the quality of which is variable), duplication of information (different clinicians often have different sections), poor indexing of information, inconsistency of information (no way to verify entries), numerous formats, and difficulty of access and evaluation of specific content.<sup>9</sup>

The problem-oriented medical record (POMR) is one well-known example of standard reporting structures for charting patient medical information, supplanting the traditional historical clinician narrative with a clear and rational format.<sup>10–12</sup> In the POMR, all diagnostic and treatment procedures are linked to a particular patient problem. The POMR structure provides a template for the comprehensive picture of a patient's clinical health and social welfare<sup>13,14</sup> as well as a road map of the clinician's thought process from patient data collection to diagnosis and treatment.<sup>15,16</sup>

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Clinical practitioners have customized the POMR structure to ensure complete and readable data in a utilizable, relevant format.<sup>17</sup> One of the best known of these data entry frameworks is the "SOAP" format (subjective, objective, assessment, and plan).<sup>18</sup> The "SOAP" format reflects how clinicians structure clinical information toward the ultimate purpose of solving patient problems, imbuing the data collection and analysis processes with detail, accuracy, scientific objectivity, and reproducibility.<sup>19</sup>

The POMR structure in paper-based records has been less successful in the care of chronic disease patients. The sheer volume of examinations, tests, consultations, prescriptions, and hospitalizations occurring over time makes it difficult to efficiently document and access the patient's history of medical events.<sup>20</sup> The POMR structure is not optimal for recording multiple, frequent follow-up or maintenance visits, and there may not always be consensus over what constitutes the most clinically relevant way to organize voluminous patient data.<sup>21,22</sup>

For EPR systems, structured entries (e.g., codes, classifications, and nomenclatures) are most frequently used.<sup>23</sup> Because they resemble paper-based formats, these highly structured data formats are well accepted by physicians and encourage a greater standardization of data entry, thus, promoting collaborative and goal-directed treatment planning.<sup>24</sup>

For patients, however, these structured entry formats may limit usability. For example, it has been shown that closed-ended questions followed by free-text entry are a preferred method of information entry among patients.<sup>25</sup> Although free-text entries are probably easier to adapt to a patient's understanding of their disease, this format limits the system's ability to collect aggregate data based on more finite or standardized entries and thus is likely to be less attractive to health care organizations.

## Theoretical Framework

The critical research tradition recognizes that many social systems have characteristics that restrict the capacity of some individuals to realize their full potential. While people possess the ability to consciously act to change these restrictive social systems, their actions can be constrained by the presence of social, cultural, and political domination, natural laws, and limited resources.<sup>26</sup>

The role of research in the critical tradition is not only to identify and explain social phenomena, but also to critique the unjust and inequitable conditions from which people require emancipation. To achieve this, researchers observe people acting and interacting in real social settings and attempt to understand the meaning of these actions and interactions from people's own perspectives and within the social settings' contextual restrictions.<sup>27</sup>

"Classical" critical social theory has been applied to empirical studies of information systems outside of health care, including e-mail communication and the evaluation of system design and development frameworks.<sup>27,28</sup> In these instances, researchers develop solutions that address social and organizational restrictions by partnering in studies with research subjects and other stakeholders.

Critical social theory has been utilized in nursing, medicine, and social work to help enrich the understanding of patient experiences in health care. In particular, critical approaches have been used in literature reviews and other reports to help expose discrepancies and contradictions between the traditional structuring of the health care system, the evaluation and treatment of patients by physicians and nurses, the creation of hospital policies, and how patient empowerment, knowledge, and participation are valued and operationalized in actual clinical contexts.<sup>29-32</sup>

Critical social theory has been used to broaden the appreciation of the dynamic social implications of information and communication technology in traditional public health care institutions.<sup>33</sup> To our knowledge, however, a critical research perspective has never been used in the context of a systematic literature review seeking to inform the development of an evaluation framework for patient-accessible information systems in hospitals.

## Methods

A systematic review of the literature was performed with the keywords *medical records* and *structure*. Primary inquiry of the following databases identified a total of 783 citations: Medline (1966–2003), CINAHL (1982–2003), CANCER-Lit (1975–2002), HealthSTAR (1975–2003), EMBASE (1980–2003), the American College of Physicians (ACP) Journal Club (1991–2003), the Cochrane Central Register of Clinical Trials, the Cochrane Database of Systemic Reviews (through 2003), and the Database of Abstracts of Reviews of Effects (through 2003). Detailed examination of titles and abstracts identified citations specifically addressing the structural issues of medical records. Articles written in languages other than English were included if an English-language abstract was available and the content provided material of pertinence. A final total of 94 articles were reviewed for the Results section of this report.

To better understand how structural limitations can be overcome to promote patient use of an EPR, literature containing empirical reports of patient utilization of medical records (both electronic and paper based) was systematically searched using the following MeSH keywords in the Medline (1966–2003) database: *medical records systems—computerized*, *hospital information systems*, *computer communication networks*, *medical records*, and *electronic patient records*. Excluding the latter, all then were cross-referenced systematically first to the term *utilization* (674 citations) and then to the term *patients*, which identified 86 abstracts. Review of these abstracts found a final tally of 31 unique citations pertinent for inclusion.

The 150 citations identified in the Medline search using keyword *electronic patient records* were individually evaluated, finding nine pertinent English-language abstracts for inclusion. Six additional documents illustrating specific characteristics of patient-access-EPR projects were found on the World Wide Web through an online search using the Google proprietary Web search engine. Thus, a final total of 46 articles were reviewed for the empirical content of the paper.

## Results

The systematic review was designed to uncover literature on the relationship between medical record structure and

patient utilization of health care information systems. A critical paradigm was used to frame the examination of the literature, and through this process, four factors were repeatedly identified whose presence (or absence) appears to attenuate (or enhance) the impact of medical record structure on patient utilization of their medical records. These included a primacy of attention to environmental pressures, a highly physician-centered organizational identity, a collaborative organizational culture, and a strong organizational belief in the value of patient-centeredness in health care.

## Environmental Pressures

### *Orienting toward a Single, Lifelong Electronic Health Record*

The longitudinal lifelong electronic record appeals in particular to policy makers and epidemiologists. This format ostensibly unifies all of a patient's health information from disparate sources, resulting in better surveillance of health problems and a more comprehensive understanding of trends in service utilization.<sup>34</sup> Such a person-centered, centralized resource delivered over the Internet can promote wellness and self-monitoring of health status by patients<sup>35</sup> as well as overall health system efficiency by encouraging health care workers to adopt and develop standardized information collection and service delivery practices.<sup>36</sup>

The achievement of one singular record requires the establishment of a standardized medical lexicon.<sup>37</sup> There are several international and national consensus working groups that seek to develop such a lexicon, although none have prioritized patient vocabularies in their structures. However, realization of the goal of patient-access is likely to be restricted by legal and public policy as well as data and security requirements, patient confidentiality concerns, and interorganizational incompatibilities.<sup>38</sup> For example, a universal patient indicator, mandated in the United States through the Health Information Portability and Accountability Act (HIPAA) to be implemented by 1998, has failed to be realized as of 2003.

### *The Need for a Standard, Universal Language*

Paper-based records have historically suffered from a lack of standardization in structure, content, and format.<sup>39</sup> For electronic records, there are several choices for standards of information formats, lexicons, or system structures available to health care institutions.<sup>40</sup> For example, there exist numerous attempts at standardized representations of clinical vocabularies based on everyday medical lexicons or "natural" language of clinicians for EPR systems such as SNOMED, MeSH, Read Codes, and others.<sup>41-44</sup> Data definitions, particularly in free-text entries can vary from organization to organization or clinician to clinician, depending on the standards used or individual practitioner training experiences.<sup>45,46</sup> Different classification schemata for diagnoses and procedures may be used by diverse institutions and in separate jurisdictions, depending on the requirements of the local information systems or the status of their upgrading processes.<sup>47</sup> For hospital EPR systems, standards of language, messaging, terminology, structure, and documentation created by organizations such as Health Level Seven (HL7) have been formulated based on the established processes and procedures of software vendors, health care providers, governments, insurers, and health maintenance organizations.<sup>48</sup>

## Physician Centeredness

### *The Record Is a Tool for Physicians*

Physicians are considered the central stakeholders whose needs determine systems in health care,<sup>49</sup> including the requirements of structure and data content for paper-based medical records and chart summaries<sup>50</sup> as well as newly implemented EPR systems in health care organizations.<sup>51,52</sup> Most EPR systems are modeled after the work processes of particular health care providers,<sup>53-57</sup> and the majority of systems discussed in the literature are designed for physician use or for communication among physicians or between physicians and the hospital.<sup>58,59</sup> This can also be observed in applications designed for comprehensive, patient-centered, disease management programs in which patients are considered to be integral partners in management of their chronic disease.<sup>60</sup>

In some cases, the structure of EPR systems can shape the physician's cognitive behavior and work processes, such as structuring data entry requirements primarily according to system capacities and not according to clinical acumen, generating additional work for the physician separate from patient care.<sup>61</sup> These, in turn, may compromise utility of the system even for physicians, corrupting the overall organization of information and knowledge in the record, reducing any potential efficiency gains, and even influencing communication with the patient.<sup>62</sup>

Medical knowledge and medical lexicon representations are based on the notion that physicians approach the content of the medical record with a body of knowledge and experience that allows for their efficient usage. EPR systems tend to use these models of knowledge representation to inform their structure because the primary users are physicians.<sup>63</sup>

### *Power Differentials*

Power differentials exist in medical culture.<sup>64</sup> The physician-patient relationship is affected by a power differential, although this may not always be unwanted by both parties.<sup>65,66</sup> However, its very presence may preclude the implementation of innovations enhancing patient autonomy and participation in care, including integration of patient-access to electronic health records.<sup>67</sup> For example, community-based family physicians may approach patients in a less problem-oriented, more patient-centered manner than hospital-based physicians.<sup>68</sup> Conversely, in an acute-care hospital, a more paternalistic relationship construct may be preferred because of the presence of urgent medical situations, with patients less able or interested in participation in decision making.<sup>69</sup> In the community, patients tend to be less acutely ill even if they are afflicted with a disease that may be chronic and severe. Therefore, the type of relationship that develops between themselves and their physicians may be more conducive to greater patient autonomy and participation.<sup>70</sup>

## Collaborative Organizational Culture

### *Valuing Collaboration in System Design*

In principle, the process of information system development is guided by the functional requirements of the actual users.<sup>71</sup> Decisions on design and implementation of patient records systems in specific health care organizations are made by senior hospital administrators and information system and

technology specialists in partnership with clinician-users.<sup>72,73</sup> Care trajectories and clinical work processes must inform the structure of the system to allow for the greatest chance of infusion throughout the organization.<sup>74-76</sup> In addition, a newly implemented system should afford apparently seamless access to information housed in the organization's existing legacy systems.<sup>77,78</sup>

However, the organizational structure of the modern hospital has a territorial disconnect between the administrative and clinical functional divisions. Although both divisions may have similar end-points of value for an information system (e.g., quality improvement, efficiency, efficacy, safety), they may have different perspectives on how a new system achieves such goals.<sup>79,80</sup> Hospital administration is highly dependent on clinicians to collect the information on service delivery, budgetary priorities, and operations from which organizational decisions are based.<sup>81</sup> Therefore, the cost-effectiveness of the system, a principal determinant of return on investment, is wholly dependent on feasibility for and acceptance by clinician-users.<sup>82,83</sup>

Furthermore, the internal landscape of health care organizations can be irreversibly transformed by the introduction of any new information system.<sup>84-86</sup> Health care providers face procedural and role changes when patients have access to their records.<sup>87,88</sup> There may be little incentive on the part of either clinicians or administration to give patients access to the system if little further benefit is believed possible.

#### *Valuing Collaboration in Documentation*

Patient-focused care initiatives have been designed so that similar chronic patients are managed by a team of clinical professionals, including physicians, nurses, social workers, occupational therapists, chaplains, home care workers, psychologists, physiotherapists, and others, affording greater patient and staff satisfaction and improved operational efficiency.<sup>89,90</sup> However, each clinician often contributes data content of the medical record with their own particular voice.<sup>19</sup> That is, every individual clinician may interpret the patient's disease narrative and chart their impressions using a lexicon that may be unique to their own specialty.<sup>91,92</sup> The record then becomes a multivoiced rather than a unified representation of the patient with a trail of perspective-driven reports and entries, each implicitly claiming to represent the truth but with little communication between one another.<sup>93,94</sup> A culture that encourages active collaboration between nurses, physicians, and other clinicians in the development process of the information system as well as joint collaboration on chart note writing can result in a unified note structure that would be easier for patients to read, understand, and ultimately use.<sup>95-97</sup>

#### **Patient-centeredness**

*Valuing the Patient as a Creator and User of Knowledge*  
Patients want to have unmitigated access to, if not ownership of, their medical records.<sup>98</sup> While access to clinical practice guidelines, online evidence-based research, and other knowledge resources from within an EPR system enhance the clinical utility of the system for clinicians,<sup>99-101</sup> a patient's lack of objectivity may generate misunderstanding about the overall meaning of the content and results, and thus hinder effective learning from the data presented.<sup>102</sup> Methods to enhance active learning have to be incorporated in the record

to ensure that patients are able to understand and appreciate the significance of both personal data and supportive information.<sup>103</sup> For example, integrating means for physician-patient communication into the record structure, such as e-mail linking or online question-and-answer bulletin boards or discussion forums<sup>104-106</sup> enhances not only the value of record access by immediately guiding patients to the appropriate use of information at the time of access but also by emphasizing the central important presence of the physician-patient relationship<sup>107</sup> even in cyberspace.<sup>108</sup> An online knowledge repository linked to the patient's record,<sup>109</sup> akin to frequently asked questions (FAQs) on a commercial Web site, provides an immediate information resource for patients who may not want or need to speak directly with a physician.<sup>110</sup>

#### *Appreciating the Benefits of Patient Access to Health Data*

Patient access to and use of personal data is a helpful adjunct to effective patient care,<sup>111</sup> leading to greater patient empowerment,<sup>112</sup> and contributing to overall improvement in health outcomes.<sup>113</sup> Note reading by patients results in significantly improved physician-patient communication and less confusion about health problems.<sup>114</sup> Patients themselves believe that compliance with treatment regimens may improve if they have the opportunity to read their own charts and have access to test results presented in a clear, graphic manner.<sup>115</sup> Medical record sharing has also been found to influence patient adherence to health promotion recommendations,<sup>116</sup> but this and other benefits may be somewhat limited by a person's age or medical history.<sup>117</sup>

Patient access to personal medical data may act as an adjunctive therapeutic intervention, enhancing comfort,<sup>118</sup> increasing self-reported satisfaction,<sup>119</sup> augmenting a sense of empowerment over disease and health,<sup>120</sup> and significantly improving self-reported health status and self-assessed physical functioning in patients with chronic disease.<sup>121</sup>

Other randomized, controlled trials of patients receiving summaries or supplemental records, however, fail to show statistically significant differences over controls in hospital readmission rates, in lengths of sick leaves, in numbers of postdischarge emergency visits,<sup>122</sup> or in patient satisfaction, global health status, and quality of life.<sup>123</sup>

#### *Customization: Not All Patients Are the Same*

Access to medical records may not always be associated with their effective utilization by patients. For example, patients with acute and chronic problems have different sets of needs, and these may be reflected in the respective gains from electronic records.<sup>124</sup> Patients with intermittent acute medical problems may derive greater utility from a summary interface such as a smart card.<sup>125</sup> Chronic diseases tend to support long-term partnerships between physicians and patients<sup>126</sup> and may benefit from the integration of records access, portability, and personal input<sup>127</sup> as well as online tools for decision support and knowledge management<sup>128</sup> to measurably influence health outcomes over time.<sup>129</sup>

Future studies of chronic patients may yield disease-specific EPR usage patterns. For example, diabetes home-based self-management programs, with daily self-testing, may derive greater benefit from having access to electronic records.<sup>130</sup>

### *Valuing Patient Contributions to the Medical Record*

The integration of patient-generated narratives of disease experiences in the medical record improves the relevance of the record,<sup>131</sup> which also serves to broaden the health care provider's understanding of the patient's illness and, thus, enhancing the quality of health care and improving the outcomes of clinical decision making.<sup>132</sup> A patient diary format containing both structured questionnaires and free-text elements appears to be well accepted by patients in chronic disease situations and can provide a patient-focused way for health care organizations to longitudinally monitor health outcomes such as quality of life during treatment regimens.<sup>133</sup> Diaries incorporated in the record have also been found to be valid and reliable narratives of patient experiences with acute, episodic, and chronic physical and mental illnesses.<sup>134–136</sup> Well-structured and evaluated disease-focused questionnaires provide a supplemental validation of the content in patient narratives and may assist physicians in the objective measurement of trends in a chronic patient's self-assessment of his or her health status over time.<sup>137</sup>

Importing a dialogic capacity to the EPR also has the added advantage of operationalizing a second, virtual layer of social interaction between patients and physicians. This validation of the patient's contribution mediates improved physician-patient collaboration and communication.<sup>138,139</sup> The resultant partnership empowers patients to take greater ownership of the outcomes of their care, a phenomenon already discovered from studies on the effects of shared ownership of paper-based records.<sup>140,141</sup>

Conversely, lack of a partnership has been found to compromise effective communication and severely limits patient utilization of medical records. In one clinical trial, between 20% and 40% of cancer patients were unable to use their shared records in their clinical visits because they felt intimidated or their physicians were either disinterested or too busy.<sup>142</sup>

### *Accounting for Patient Social Networks*

Patients often partner with family members, nonmedical caregivers, and other organizations to manage their health care problems and address their health care needs. Use of information systems may be shared by patients or their caregivers with members of their social network to enhance understanding, find support, and alleviate fear.<sup>143–145</sup> Other patients accessing a computer system from home may learn to support each other for the enhancement of understanding and the fulfillment of information needs.<sup>146–149</sup>

Much health information, including that contained within the medical record is not well understood by many patients. Health information seekers consult health professionals and other members of their social network, including the Internet, when information is unclear or apparently incomplete.<sup>150</sup>

## **Proposal of a Conceptual Framework**

A preliminary framework for evaluating the impact of medical record structure on patient utilization of an EPR is proposed (Fig. 1). Focus by the organization on external factors in the environment seems to mitigate greater utilization of an EPR system, as this can translate into less concern for the human factor elements that make a system usable by all levels of users. A physician-centered organiza-

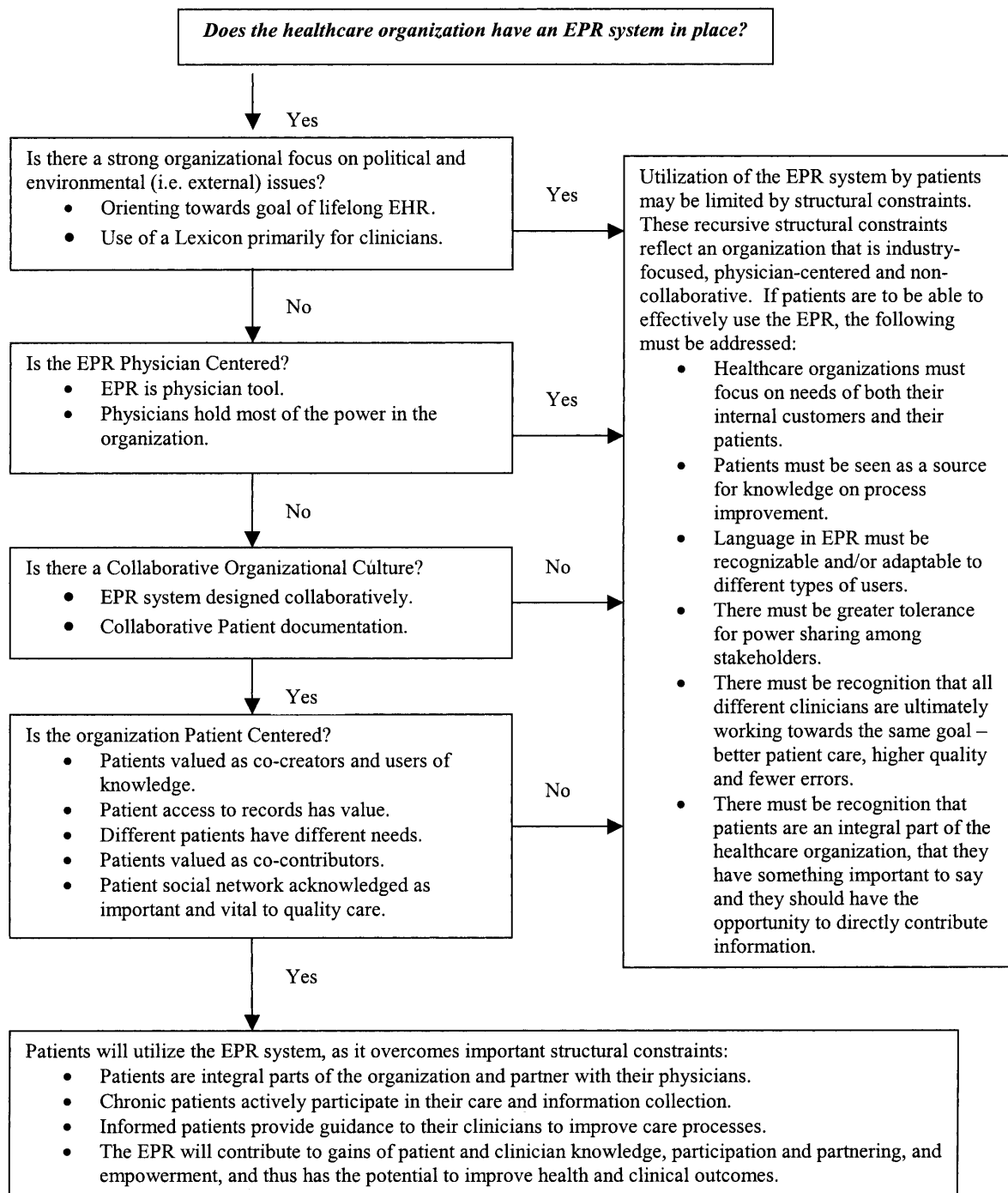
tional culture may be a disincentive on some levels for patient participation in their care, possibly by promoting the perception of inaccessibility of medical records, resulting in a lower likelihood of EPR system utilization by patients. In contrast, the presence of an organizational culture of greater collaboration appears to facilitate utilization, overriding many structural restrictions to patient use. A global appreciation for the role of patients as partners can overcome EPRs' innate structural limitations as well, thus facilitating EPR utilization by patients.

## **Applying the Framework to Projects for Patient Access to and Use of EPR Systems**

Informatics for Diabetes Education and Telemedicine (IDEATel) is a Web-based telemedicine project with disease-focused patient access to an electronic patient information system. Outcomes are to be measured with standardized and validated instruments and include clinical findings, process-of-care, quality of life, satisfaction, and service utilization in a randomized, controlled trial.<sup>151</sup> The case management graphic interface for presentation of data to patients is a customized module of a proprietary software product.<sup>152</sup> IDEATel demonstrates a patient-centered focus by addressing the specific needs of patients living with a particular chronic disease with a preliminary qualitative analysis of interviews and questionnaires of patients prior to development. It is unclear to what extent patients actively played a role in the design and implementation processes.

The Patient Clinical Information System (PatCIS) is the patient portal to a Web-based clinical information system (WebCIS) developed by the Columbia University Department of Medical Informatics. A small cohort of patient-users have accessed the system on average a few times a month, with the majority of system encounters involving patient access of laboratory test results.<sup>153</sup> WebCIS is developed from the perspective of users, although the PatCIS patient interface has been adopted from the physician interface with little alteration. PatCIS has been evaluated with online questionnaires, user activity tracking software, and e-mail communication for a period of about two years.<sup>154,155</sup> Although there has been some reported impact on physician-patient relations, little is known about the impact of PatCIS on patient self-efficacy, self-management trends, or knowledge acquisition.<sup>156</sup> There is a physician-centered focus with physicians' needs determining the portal's format, the selection of patients, the important outcomes to measure, and the type of content. Patient satisfaction is assessed, with no indication of the patients' role in design. There is no consideration of organizational or environmental factors reported in the literature.

The Patient-Centered Access to Secure Systems Project (PCASSO) allows patient access to their medical records in a highly secured environment.<sup>157,158</sup> There are no reports of baseline interpretive in-depth stakeholder or user analyses, although patients and physicians report satisfaction with the availability of records on the Internet and interface usability.<sup>159</sup> The immediacy of access to health data through the PCASSO interface generates questions from patients, stimulating a greater need for user support. However, the researchers do concede a negative impact from focusing on the external environment by pointing out that a concentration



**Figure 1.** Evaluation framework for assessing the impact of medical record structure on patient utilization of patient-accessible electronic medical records. EPR = electronic patient record; EHR = electronic health record.

on security and privacy assurances for government and the public has negatively affected accessibility, utilization, and satisfaction.

The System to Provide Patients Access to Records Online (SPPARO) offers Web-based access to medical records and is being evaluated in a cohort study of patients with congestive heart failure. Impact of the system on patients is to be measured with questionnaires evaluating patient self-efficacy, treatment adherence, functional status, disease knowledge, doctor-patient communication, and overall satisfaction.<sup>160</sup> A

preliminary survey of study subjects found that technically motivated patients are less likely to believe that they will be offended and confused by the content in their EPR, whereas their physicians remain more concerned about the risks and more skeptical about the potential benefits.<sup>161</sup> SPPARO has emphasized the supportiveness of organizational culture as a success factor in the project's implementation. Concerning the value of collaboration, SPPARO has involved all levels of the organization: administrators, clinicians, information specialists, and patients.

## Discussion

Patient access to a health care organization's EPR system diverges from the traditional role expectation of the patient in the social system of the hospital and can have profound repercussions on the functioning of that system.<sup>162</sup> For one, it creates a supplemental, virtual level of social interaction through which patients can communicate with their clinicians and participate in their care. By having access to their own health data simultaneously with their clinicians and actively contributing information to their own record, patients can develop a stronger sense of ownership of their data, hence, becoming co-constituents of the system and, by extension, contributory members of the health care organization.

However, patients and physicians differ in how they utilize, internalize, and contextualize health data.<sup>163</sup> Patients may not possess a shared understanding of medical terminology, and this impedes use and may even cause greater uncertainty and fear unless patients are well trained in the meanings and nuances of clinical language. Furthermore, patients living with long-term chronic disease may have difficulty understanding and relating their disease management experience to the standardized lexicons prescribed by governmental agencies and legislation.

What's more, while it is less well known what patients do with their records over the long term once they have access to them,<sup>153</sup> patients are not likely to have the same requirements as physicians for what they would like to see in an EPR,<sup>164</sup> even if they do actively participate in their own care. Patients accessing a clinician-structured system may become resistant to adapting their self-management to the knowledge, lexicons, and patient management processes of clinicians, making the system frustrating for patients, and thus limiting its long-term usability.

Currently, the structures of prototype EPR systems identified in this review are constrained by the same organizational, cultural, and environmental influences as paper-based records. This suggests that methods currently used in system research and development may not allow the online patient-accessible EPR to reach its full potential as a tool to promote patient self-efficacy, empowerment, and personal responsibility for health outcomes.

However, a patient-centered organizational culture can override structural barriers to patient use of an EPR system, even if the system is still primarily designed for clinician use. Ideally, a patient-accessible electronic medical record is location-independent, and the collaborative ownership of the record and its content should reflect a negotiation of the needs of all stakeholders.<sup>165,166</sup> While efforts should also be made to comply with design principles based on human-computer interaction research, as poor design can complicate the navigational process for patients and increase demands on their attention, perception, language, and memory, it is also essential that system designers appreciate how patients use information in self-management, how they perceive benefits from an EPR, and how they are permitted to interact with their physicians and the health care organization. The structural design of a patient-directed system should aim to match the "workflow" or fit the "job description" of patients living with chronic disease within the context of the cultural boundaries of their health care organization, as well as follow

established standards, accommodate flexibility, and focus the patient's attention on data presented in an easily navigable and comprehensible format. Preliminary experience with patients in our own institution suggests that direct interaction between patients and interface designers *throughout* the design and development process is critical to ensure successful adoption and implementation of a patient-usable EPR.<sup>167</sup>

Thus, innovative patient-centered approaches to the design and evaluation of patient-accessible EPR systems are needed to inform newer systems that can override embedded, long-established structural constraints to patient use. For example, action research (AR), a qualitative critically rooted methodology used in the fields of community health, social work, and nursing, has proven to be useful for both the identification of contributory factors in systemic and organizational change and the subsequent examination of the resultant change process.<sup>168</sup> AR fosters collaboration between academic researchers and subjects,<sup>169</sup> empowering the participants themselves to direct research priorities toward the improvement of their work practices, their organizations, their communities, and their lives.<sup>170</sup> A participatory AR approach to the development process of an EPR patient access project operationalizes the partnership between clinicians, patients, and the hospital, resulting in a tool that can prevail over the institutionalized constraints embedded in traditional and electronic medical record structure, thus more effectively attending to the information needs, preferences, and usage behaviors of patients with chronic disease.

## Conclusion

The structure of electronic patient records integrates important constraints that can determine their long-term use by patients. The proposed critical evaluation framework provides guidance for researchers in identifying the cultural, organizational, and environmental factors implicit in medical record structure, stressing the importance of selecting innovative, collaborative system research and development methodologies to account for these constraints, thereby maximizing the potential of personal information housed in the EPR to improve clinical outcomes for patients with chronic disease.

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